

JOB DESCRIPTION

Engagement and Support Officer - Wales

Job title:	Engagement and Support Officer - Wales
Employer:	Genetic Alliance UK
Based at:	Home based
Line Manager:	Director of Support
Salary:	£25,606-£28,240 (pro rata) depending on experience
Term:	21 hours a week, fixed term for three years This post is subject to a six-month probation period

About Genetic Alliance UK and SWAN UK (syndromes without a name):

Genetic Alliance UK is the national charity of over 200 patient organisations supporting all those affected by genetic conditions. Our aim is to improve the lives of people affected by genetic conditions, ensuring that high quality services and information are available to all who need them.

SWAN UK (syndromes without a name) is a support network run by Genetic Alliance UK. It is the only dedicated support in the UK for families of children affected by a syndrome without a name – a genetic condition so rare it may never be diagnosed. We enable families to make contact with others who understand the unique challenges of raising a child affected by an undiagnosed genetic condition, offer access to information and support through our online forums and our Local Networks, run regular free events to bring families together and provide opportunities to make precious memories.

Role:

This role is central to the development of the support we offer to families affected by rare and undiagnosed genetic conditions in Wales. Working closely with the Policy and Engagement Manager for Wales, the post holder will be line managed by the Director of Support (based in London) to deliver information and support tailored to the needs identified by Welsh families.

Key responsibilities:

Assist with the development of Wales-specific support and information for parents of children affected by rare and undiagnosed genetic conditions.

- Involve local parents through a variety of online activities and consultation events to help produce an early intervention information toolkit for Wales - The Rare Resources (Wales).

Genetic Alliance UK

contactus@geneticalliance.org.uk
geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

- Deliver outreach activities and events (including well-being activities, family events and information events) to engage with parents of rare and undiagnosed genetic conditions and increase Welsh membership of SWAN UK.
- Help recruit, train and support Welsh volunteer Parent Reps.
- Assist with the facilitation of the SWAN UK Welsh Facebook Group.
- Work in partnership with key local organisations to deliver holistic support.

Raise awareness of rare and undiagnosed genetic conditions.

- Be the local point of contact for enquiries.
- Help develop relevant and high-quality information in English and Welsh to increase engagement and understanding of the impact of rare and undiagnosed genetic conditions.
- Network with local services and organisations to educate local professionals.
- Help develop and implement the communications strategy for the annual Undiagnosed Children's Day and monitor its impact.
- Recruit and support Welsh volunteers from the rare and undiagnosed community to share their stories, be media volunteers and take an active role in our outreach and policy activities.

Assist with the monitoring of our work against specified project outcomes.

- Maintain records of activities and the impact of our work.
- Help recruit participants to take part in the project evaluation.

Any other tasks as reasonably required by Genetic Alliance UK.

Education and qualifications

- Graduate level or equivalent experience.

Essential qualities, skills and experience

- Experience of working in a similar role developing information and/or supporting vulnerable people.
- English and Welsh language fluency (written and spoken).
- High level of IT literacy with experience of social media platforms including Facebook, Twitter and Instagram.
- Outstanding written and verbal communication skills with a strong attention to detail.
- An empathetic attitude and enthusiasm for understanding the complexities and impact that undiagnosed and rare genetic conditions can have on family life.
- Excellent organisational skills and the ability to effectively and independently organise own time, plan ahead, keep records and manage and prioritise deadlines.
- A creative, ideas driven attitude with the ability to work independently and demonstrate initiative whilst working as part of a remote team.
- Ability to work occasional evenings and weekends and occasionally travel in the UK, including some overnight stays.
- A commitment to the aims and objectives of Genetic Alliance UK and SWAN UK.

Desirable qualities, skills and experience

- Experience of working with families of disabled children.
- Experience of working with volunteers in a paid or voluntary capacity.
- Experience of organising events.
- Knowledge of the Welsh education, health and social care system

Application details:

- Deadline for applications: Friday 13 November.
- Interviews: week of 23 November.
- Start date: As soon as possible.

Please email a CV and cover letter (in English) to: Lauren Roberts, Director of Support: recruitment@geneticalliance.org.uk.

Your cover letter should provide detail on why you are suitable for this role and include examples of previous work, whenever possible. Please save your documents as Fullname.CV and Fullname.Coverletter and state your name and post applied for in the email subject line. Applications without cover letters will not be considered.

For more information, please visit undiagnosed.org.uk and geneticalliance.org.uk.